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Impact of palliative home care support on the quality and costs of care at the end of life: a population-level matched cohort study

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ABSTRACT

Objectives To evaluate the impact of palliative home care support on the quality of care and costs in the last 14 days of life.

Design Matched cohort study using linked administrative databases.

Setting All people who died in Belgium in 2012 (n=107 847).

Participants 8837 people who received palliative home care support in the last 720 to 15 days of life matched 1:1 by propensity score to 8837 people who received usual care.

Intervention Receiving the allowance for palliative home patients, multidisciplinary palliative home care team visit or palliative nurse or physiotherapist visit at home.

Main outcome measures Home death, number of family physician contacts, number of primary caregiver contacts, hospital death, hospital admission, intensive care unit (ICU) admission, emergency department (ED) admission, diagnostic testing, blood transfusion and surgery. Total inpatient and outpatient costs. All outcomes were measured in the last 14 days of life.

Results In the unmatched cohort, 11 149 (13.5%) people received palliative home care support in the last 720 to 15 days of life. After matching, those using palliative home care support had, compared with those who did not, more family physician contacts (mean 3.1 [SD=6.5] vs 0.8 [SD=1.2]), more chance of home death (56.2%vs13.8%; relative risk [RR]=4.08, 95% CI 3.86 to 4.31), lower risk of hospital admission (27.4%vs60.8%; RR=0.45, 95% CI 0.43 to 0.46), ICU admission (18.3%vs40.4%; RR=0.45, 95% CI 0.43 to 0.48) or ED admission (15.2%vs28.1%; RR=0.54, 95% CI 0.51 to 0.57). Mean total costs of care were lower for those using palliative home care support (€3081 [95% CI €3025 to €3136] vs €4698 [95% CI €4610 to €4787]; incremental cost: −€1617 [p<0.001]).

Conclusions Palliative home care support use positively impacts quality of care and reduces total costs of care at the end of life in Belgium. Policy makers and healthcare practitioners should increasingly focus on communicating the existing options for palliative home care support to patients and their caregivers.

Strengths and limitations of this study

- By using nationwide administrative data on every death over one whole year, our findings are generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain under-represented subgroups and lack the strength necessary for generalisability.
- A matched cohort study design with a high-quality matching is the best possible technique to evaluate the impact of policy on quality and costs of care, given ethical and practical concerns.
- No previous work has evaluated the impact of all palliative home care support available in one country for the full population.
- Our operationalisation of palliative home care support as the use of any of available policy measure increases the reproducibility of our study in other countries and allows comparison studies that focus on the impact of other existing types of palliative home care support, especially in countries with similar health care service delivery models and funding.
- Important aspects of quality end-of-life care are not visible in administrative data, such as quality of communication, existential or psychological care. Qualitative research can complement our findings.

BACKGROUND

A majority of the growing population encountered with chronic and life-limiting illnesses prefers to receive high-quality care and to die at home.[1 2] Palliative home care support aims to meet the needs of these people by managing symptoms, improving quality of life and preventing avoidable healthcare interventions such as hospitalisations at the end of life.[3] It is estimated that palliative care could be beneficial in 38%–74% of all deaths worldwide.[4] In recent years, policy makers internationally have focused on promoting the integration of palliative care services into the community and on developing supportive

policy measures for palliative care at home to meet the growing demand for high-quality home-based palliative care and to reduce costs related to acute hospital care use at the end of life.[5–7] Several countries offer palliative home care support in the form of multidisciplinary palliative home care teams, palliative nursing care at home or financial support for those wanting to receive palliative care at home.[8–11]

The impact of using palliative home care support on the quality and costs of care at the end of life remains poorly evaluated.[12] A Cochrane review that included 23 studies found that use of home palliative care services more than doubled the odds of dying at home and reduced symptom burdens.[13] Six studies focused on costs and reported up to 35% lower costs in the intervention group compared with a control group. Only one study reported statistically significant differences, but the authors pointed out that 'the existence of economically significant differences [in the other studies] cannot be ruled out due to small sample sizes unlikely to have sufficient power to detect statistical significance'. Another recently updated Cochrane review included four trial studies that evaluated 'hospital at home' services, demonstrating the positive impact of this type of home-based end-of-life care on the chances of having a home death, but results on hospital admissions and healthcare costs varied and were found inconclusive.[14]

However, traditional experimental study designs, such as those evaluated in the above-mentioned reviews, are limited due to ethical and practical concerns (eg, it would be illegal to refrain patients from receiving any palliative home care in a trial). Therefore, they are not suitable for evaluating the impact of palliative home care support that are available nationally to everyone across a healthcare system.[3] A matched cohort study design with a high-quality matching on the propensity of receiving palliative home care is the best possible technique to evaluate this impact.[15] The increasing availability and improving quality of routinely-collected databases and the technical possibilities of linking data from various sources have opened up new possibilities for such designs.[16] Three retrospective cohort studies using matched controls found an impact of palliative home care support on reducing hospitalisations at the end of life and on lower chances for hospital deaths in Canada, England and the USA.[17–20] Findings from another retrospective cohort study suggested that a proactive home-based palliative care programme 'helped to avoid the escalation in hospital use and costs commonly seen in the final months of life'.[21] However, these studies focused only on a limited number of outcomes as indicators of quality of end-of-life care (hospital use and place of death) and only one focused additionally on costs, without distinguishing inpatient and outpatient costs. None of the studies used population-level national data, therefore limiting the findings to one specific province or region.

In Belgium, palliative home care support is available in the form of: (1) a multidisciplinary palliative home care team, (2) palliative home care nursing or physiotherapy and (3) the allowance for palliative home care patients, available twice and meant for non-reimbursed palliative care-related costs. These supportive policy measures are entirely free to the patient and their informal caregivers. Using linked register-based databases on all deaths in Belgium, the current study aims to evaluate the impact of using palliative home care support on the appropriateness and costs of care in the last 14 days of life on a population level.

METHODS

Study design

We conducted a matched cohort study on all deaths in Belgium in 2012, using linked data from eight administrative databases. An individual that used at least one type of palliative home care support was matched to an individual that used no palliative home care support. To reduce selection bias between the groups and to balance measured covariates across them, we used propensity score matching.[15] We followed an extension of the Strengthening the Reporting of Observational Studies in Epidemiology guidelines for reporting observational studies to report the propensity score matching analysis.[16]

Study setting and participants

The study was conducted for all those who were registered with a Belgian sickness fund at time of death in 2012 (98.8% of all deaths). We excluded people younger than 18 years and those who had permanent residence in a nursing home during the last year of life. Additionally, to avoid any overlap between the timing of exposure and the timing of the outcomes, we excluded those for whom palliative home care support was initiated for the first time in the last 14 days of life. Figure 1 presents the study population selection process.

The data used involved eight administrative databases, linked on an individual level using a unique identifier by a third party responsible for data protection and linkage in Belgium. The linked data included person-level reimbursed healthcare use in the last 2 years of life (recorded as nomenclature codes) including dispensed medication in the hospital and community pharmacy in the last 2 years of life (recorded as Anatomical Therapeutic Chemical Classification System (ATC) codes). For all healthcare data, the exact date of delivery (coded as number of days before death) is recorded. Additionally, the data include demographic data, fiscal data (ie, net taxable annual income) and death certificate data (including underlying cause of death, coded using International Statistical Classification of Diseases, Tenth Revision (ICD-10) codification).[22] The data linkage process and content is described in detail elsewhere.[23]

Patient and public involvement

We used previously validated quality indicators (QIs) for end-of-life care to measure appropriateness and

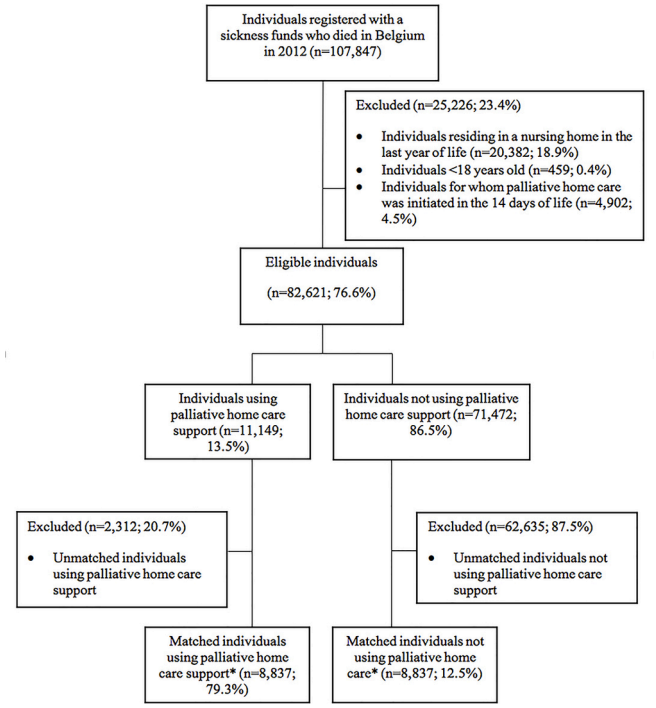

Figure 1 Flow chart of the study population selection.

inappropriateness of end-of-life care on an aggregated level. Patients were not directly involved in the design of the study or development of the QIs. The design of the study, using population-level decedent data, did not allow to disseminate results to or involve observed patients in the development of the research questions or outcome measures.

Exposure group

Our exposure group consisted of people who used at least one type of palliative home care support between the last 720 and 15 days of life (see box 1). We included all persons receiving palliative home care support for the longest time frame available in our data, that is, up to 720 days before death. We did not want to exclude persons on the basis of a (retrospectively) predefined time frame, as this information (time before death) would not be known using a prospective design. The inclusion criteria were: (combined by 'OR'): (1) having received the allowance for palliative home patients, (2) having a visit by a multidisciplinary palliative home care team visit or (3) having a visit by a palliative nurse or physiotherapist at home. Using specific nomenclature codes, we could identify delivery, health insurance-reimbursed cost and timing of a specific palliative home care support. The data were sorted to identify the earliest use of palliative home care support when multiple measures were used.

The Belgian health system is primarily funded through social security contributions and taxation, with a compulsory national health insurance, which covers the whole population. Compulsory health insurance is combined with a private system of healthcare delivery, based on independent medical practice, free choice of service provider and predominantly fee-for-service payment. It is important to note that all healthcare insured people in Belgium have the legal right to access palliative home care support. Family physicians play a gatekeeping role in this: they remain responsible for all care provided at home and need to give their written permission to initiate any of the palliative home care support. Receiving any of these was chosen as exposure because we considered the different types of support to be an indication of the same intervention: initiation of palliative home care. However, sensitivity analyses were performed in which each separate support type is selected as the basis for the exposure group.

Box 1 Description of the exposure: palliative home care support in Belgium

Policy measures to support palliative care at home, here defined as 'palliative home care support', exist in Belgium since 1985.[30] In 2002, palliative care was recognised by Belgian law as a right for all Belgian citizens. Since then, seriously ill patients with a short life expectancy (defined by law as 'more than 24 hours and less than three months') and an intention to die at home are eligible to receive specific supportive measures from the Belgian government.[32] These are:

a. The use of a multidisciplinary palliative home care team: which includes at least one general practitioner, two nurses and an administrative assistant. The main goal of the multidisciplinary palliative home care teams is to advise family physicians, health professionals, counsellors, informal carers and volunteers involved in the provision of palliative home care of a patient and to organise and coordinate the provision of that palliative care at home between different care providers. The use of these teams is free of charge for the patient and not limited in time.
b. Palliative home care nursing or physiotherapy: type of nursing care or physiotherapy at home, differing from standard nursing care or physiotherapy at home for heavily dependent home-patients in the number of caring tasks provided and round-the-clock availability. Free of charge for the patient.
c. The allowance for palliative home patients: a lump sum of €647.16 (in 2012), which is obtainable twice (possibility to claim a second after 1 month) and meant to cover for non-reimbursed or partially reimbursed costs that are related to the provision of palliative care at home (eg, certain medicines, care materials and tools).

Non-exposure group

People who did not use palliative home care support in the last 2 years of life were included in the non-exposure group.

Outcomes for appropriateness and inappropriateness of end-of-life care

We used QIs for appropriate and inappropriate end-of-life care that were developed using the RAND/UCLA Appropriateness method that aims 'to combine the best available scientific evidence with the collective judgment of experts to yield a statement regarding the appropriateness of performing a procedure at the level of patient-specific symptoms, medical history, and test results'.[24] We included the following indicators for appropriateness of

end-of-life care, all pertaining to the last 14 days of life: dying at home; the average number of primary caregiver contacts; and the average number of family physician contacts. We included the following indicators for inappropriateness of end-of-life care: dying in a hospital; being admitted to hospital; being admitted to an emergency department (ED); being admitted to an intensive care unit (ICU); being submitted to diagnostic testing (ie, medical imaging, ECG or pulmonary function testing); having a blood transfusion; and having surgery.

The QIs measure the prevalence of specific medication types (recorded in the data sources using ATC codes) or healthcare interventions (recorded in the data sources as nomenclature codes for reimbursement purposes) within a specified period before death. For example, the QI 'average number of primary caregiver contacts in the last fourteen days of life' is calculated as the mean number of contacts with a family physician or other primary care professional (based on the number of relevant registered nomenclature codes) in the last 14 days of life. The development, validation process and use of these indicators to study end-of-life care on a population level is described in detail in De Schreye *et al*.[25]

Costs of end of life

Based on all specific healthcare consumption data, we calculated total healthcare costs from a third-party and patient copayment perspective, consisting of total inpatient cost and total outpatient cost for both groups. Inpatient costs included all specific intervention and medication costs in the hospital. Outpatient costs included all specific intervention and medication costs outside the hospital. For a detailed description, see online supplementary box 1. Based on the exact dates of delivery we calculated the total costs for the last 14 days of life. All costs were actualised to 2017 values based on the unit cost of all defined resources in that year.

Propensity score matching and statistical analysis

Descriptive statistics were used to describe population characteristics, stratified by having received palliative home care support (exposure group) or not (non-exposure group).

People who received palliative home care support were matched to those who did not, based on an individual estimation of their propensity for receiving palliative home care support. To calculate the propensity scores, relevant predictors for receiving palliative home care, based on previous research findings, were used as baseline covariates.[13] The following baseline covariates were used: age at death, sex, underlying cause of death (as a proxy for diagnosis using ICD-10 codification, these were recoded into: neoplasms [C00-D48], respiratory diseases [J40-44 and J47], other organ failures, ie, heart, renal and liver failure [I11-I13, I50, K70-72, N10-12 and N18-19], neurodegenerative diseases, ie, Alzheimer's disease, Parkinson's disease, motor neuron and Huntington's disease [F01, F03, G10, G12, G20 and G30], HIV/AIDS [B20-24]; other underlying causes of death were recoded as 'other'), household type, personal annual taxable income, highest attained educational level, degree of urbanisation of residence, region of residence and hospital use in the last 2 years of life (based on the criteria: 'having had at least six hospitalisations' and 'being at least 120 days in the hospital'). We used a greedy one to one case–control propensity score matching algorithm.[26] For every case, the best match was made first and a next-best match next, in a hierarchical sequence until no more matches could be made. Best matches are those with the highest digit match on propensity score. First, cases are matched to controls on eight digits of the propensity score. For those that do not match, cases are then matched to controls on seven digits of the propensity score and so on. The algorithm proceeds sequentially to the lowest digit match on the propensity score (one digit). In view of performing sensitivity analyses, we performed separate matchings with, respectively, allowance for palliative home care patients, multidisciplinary palliative home care team visit and palliative nursing care or physiotherapy at home on its own as exposure, to evaluate whether these types of support showed different results.

Two sampled t-test statistics were used to test for significant differences in age, and χ^2 statistics were used to test for significant differences in dichotomous and categorical variables describing the unmatched and matched exposed and non-exposed groups. Risk ratios were calculated to measure the differences in outcomes between the exposed group and the non-exposed group. Costs were presented as means, medians, SEs and IQRs. All analyses were performed using SAS Enterprise Guide V.7.1.

RESULTS

Study population characteristics

Of all deaths in Belgium in 2012 (n=107 847), we excluded 25 226 individuals from our study population because they resided in a nursing home (18.9% of total population), were minors (0.4%) or used palliative home care support only during the last 14 days of life (4.5%) (figure 1). Our final unmatched set consisted of 82 621 individuals of which 11 149 (13.5%) had initiated palliative home care support in the last 720–15 days of life (table 1). Before matching, the sociodemographic characteristics of the cohort exposed to palliative home care support differed largely from the unexposed cohort (eg, in cause of death, household composition and hospital use during the last 2 years of life). After propensity score matching, 8837 exposed people were matched to as many unexposed people. We performed sensitivity analyses on each support type separately with no substantial differences in the impact on the QI outcomes (online supplementary table 1).

Indicators of appropriate end-of-life care

Fifty-six per cent of the people using palliative home care support died at home, compared with 13.8% of those who

Table 1 Characteristics of people using palliative home care support (exposed) and people who did not use palliative home care support (unexposed) before and after propensity score matching

	Before propensity score matching (n=82 621)		After propensity score matching (n=17 674)	
Characteristics	**Exposed**	**Unexposed**	**Exposed**	**Unexposed**
No. of patients (%)	11 149 (13.5)	71 472 (86.5)	8837 (50)	8837 (50)
Earliest use of palliative home care in days, median (IQR)	75 (154)	/	73 (152)	/
Mean age at time of death (SD)	74.2 (12.8)	76.5 (14.2)	74.4 (12.7)	75.0 (12.3)
Sex				
Men	55.2	54.6	56.0	55.1
Women	44.8	45.4	44.0	44.9
Cause of death				
Neoplasm	74.6	20.6	72.7	72.8
COPD	2.5	4.6	2.7	2.8
Other organ failure	3.2	5.9	3.5	3.1
Neurodegenerative	4.4	5.0	4.9	5.1
Other	15.3	63.8	16.2	16.3
Household composition				
Married	60.4	44.6	60.4	61.4
Single-person household	26.2	41.5	26.7	26.4
Living together	4.1	4.2	4.0	3.6
One-parent family	6.4	6.7	6.2	5.9
Other	2.9	3.0	2.7	2.7
Education level				
No education	8.1	8.7	7.9	7.7
Primary school education	34.7	34.9	34.7	35.2
Secondary school education	44.8	45.2	45.0	44.6
Postsecondary school education	12.5	11.2	12.4	12.6
Income in quartiles*				
Lowest income quartile	29.2	26.2	28.4	28.7
Second income quartile	22.5	23.5	21.7	21.9
Third income quartile	24.1	24.5	24.3	24.8
Highest income quartile	24.3	25.9	25.6	24.6
Region				
Flemish region	66.4	53.1	65.4	64.5
Walloon region	28.8	36.8	29.6	30.4
Brussels capital region	4.8	10.1	5.0	5.1
Urbanisation				
Very high	25.1	33.7	25.7	25.6
High	28.5	27.5	29.2	28.7
Average	32.0	24.4	30.7	30.6
Low	12.9	13.0	13.0	13.7
Rural	1.5	1.5	1.5	1.5
Hospital use in the last 2 years				
≥120 days hospitalised	4.7	5.3	4.6	4.0
≥6 hospitalisations	46.5	14.7	44.5	44.6

Values are percentages of patients unless stated otherwise. All percentages are valid percentages. Missing values existed in the full population (n=107 847) for household composition (n=1399; 1.6%), education level (n=11 382; 13.1%), income (n=3563; 4.1%), region (1657; 1.9%), urbanisation (1657; 1.9%).
*Income quartiles were calculated on the full population of decedents (n=107 847).
COPD, chronic obstructive pulmonary disease.

Table 2 Indicators of appropriate and inappropriate end-of-life care in the last 14 days of life in the matched cohorts

	Palliative home care support (n=17 674)		
	Yes (n=8837)	No (n=8837)	RR (95% CI)
Indicators of appropriate end-of-life care			
Home death	56.2	13.8	4.08 (3.86 to 4.31)
Mean number of family physician contacts (SD)*	3.1 (3.0)	0.8 (1.2)	/
Mean number of primary caregiver contacts (SD)*	9.0 (6.2)	2.3 (4.0)	/
Indicators of inappropriate end-of-life care			
Hospital death	39.0	74.8	0.52 (0.51 to 0.54)
Hospital admission	27.4	60.8	0.45 (0.43 to 0.47)
ICU admission	18.3	40.4	0.45 (0.43 to 0.48)
ED admission	15.2	28.1	0.54 (0.51 to 0.57)
Diagnostic testing	27.2	63.2	0.43 (0.41 to 0.45)
Blood transfusion	2.7	5.9	0.47 (0.40 to 0.54)
Surgery	0.5	2.8	0.19 (0.14 to 0.26)

*P<0.0001 calculated using two-sided t-test statistic.
ED, emergency department; ICU, intensive care unit; RR, relative risk.

did not use palliative home care support (relative risk [RR]=4.08; 95% CI 3.86 to 4.31 (table 2). On average, people in the palliative home care support cohort had nine primary caregiver contacts and three family physician contacts in the last 2 weeks of life, compared with two primary caregiver contacts and less than one family physician contact for those in the unexposed cohort.

Indicators of inappropriate end-of-life care

Thirty-nine per cent of the people using palliative home care support died in the hospital, compared with 74.8% of the people not using palliative home care support (RR=0.52; 95% CI 0.51 to 0.54). Less people in the palliative home care support cohort were admitted to a hospital (27.4% vs 60.8%; RR=0.45, 95% CI 0.43 to 0.46), to an intensive care unit (18.3% vs 40.4%; RR=0.45, 95% CI 0.43 to 0.48) or to an ED (15.2% vs 28.1%; RR=0.54, 95% CI 0.51 to 0.57) in the last 2 weeks of life. Less people who used palliative home care support were submitted to diagnostic testing (27.2% vs 63.2%; RR=0.43, 95% CI 0.41 to 0.45), received blood transfusion (2.7% vs 5.9%; RR=0.47, 95% CI 0.40 to 0.54) or surgery (0.5% vs 2.8%; RR=0.19, 95% CI 0.14 to 0.26) (table 2).

Medical care costs

Mean total inpatient costs were lower for people using palliative home care support (€1766; 95% CI €1706 to €1826) compared with those who did not use palliative home care support (€4222; 95% CI €4133 to €4311) (p<0.001) (table 3). Mean total outpatient costs were higher for people using palliative home care support (€1314; 95% CI €1291 to €1337) compared with those who did not (€476; 95% CI €461 to €492) (p<0.001). Mean incremental total costs for exposed versus unexposed people in the last 2 weeks of life was −€1617 (SE=53.2). We performed sensitivity analyses on each support type separately with no substantial differences in the impact on the costs of care at the end of life (online supplementary table 2).

DISCUSSION

To our knowledge, this is the first nationwide matched cohort study on the impact of palliative home care support on the quality and costs of care at the end of life, using validated QIs. We found that people using palliative

Table 3 Healthcare costs in the last 14 days of life in the matched cohorts (in euro)

	Palliative home care support (n=17 674)				
	Yes (n=8837)		No (n=8837)		Mean incremental (P value)
	Mean (95% CI)	Median (Q1–Q3)	Mean (95% CI)	Median (Q1–Q3)	
Total inpatient costs	1766 (1706 to 1826)	0 (0–2724)	4222 (4133 to 4311)	3400 (513–6754)	−2454 (p<0.001)
Total outpatient costs	1314 (1291 to 1337)	1243 (449–1829)	476 (461 to 492)	251 (11–647)	838 (p<0.001)
Total costs	3081 (3025 to 3136)	2055 (1305–4227)	4698 (4610 to 4787)	3996 (1077–7124)	−1617 (p<0.001)

All costs expressed in 2017 euros. Costs were calculated using data on all reimbursed medical care costs and rounded. Total inpatient costs included all specific intervention and medication costs in the hospital. Total outpatient costs included all specific intervention and medication costs outside the hospital.
Q1–Q3 , IQR range.

home care support received more appropriate and less inappropriate care at the end of life and had lower total medical care costs in the last 2 weeks of life, compared with those who did not use palliative home care support. More than four times as many people using palliative home care support died at home than those not using palliative home care support. Fewer people in the exposed cohort were admitted to the hospital, ED or ICU, and fewer people underwent diagnostic testing, blood transfusion, or surgery in the last 2 weeks of life.

Our study found that the use of palliative home care support lowered the average total medical care costs per person in the last 2 weeks of life by €1617. Costs of palliative home care support use that was continued in the last 2 weeks of life are also taken into account. A literature review on costs of palliative care interventions in all settings between 2002 and 2011 also found that palliative care (including but not confined to palliative home care) was overall less costly than for comparator groups, despite large differences in the settings and study designs of the observed studies.[27] However, the review notes that randomisation is absent in most of the studies, highlighting the importance of controlling for confounding factors and selection bias when analysing the impact of a palliative care intervention. Our study design could to a large extent tackle these issues of confounding and bias. A retrospective study using observational data evaluated the impact of a home-based palliative care programme in Southern California on costs in four disease groups and found that participants had in the last 6 months of life monthly net savings of $4258 for cancer, $4017 for chronic obstructive pulmonary disease, $3447 for heart failure and $2690 for dementia.[21] Although generalising and comparing costs across different healthcare jurisdictions is difficult due to differences in healthcare regulations and reimbursement schemes, these numbers are in line with our findings.

Our finding that people who used palliative home care support more often died at home confirms findings in previous studies.[13 17 28–30] In Belgium, a mortality follow-back study on a sample of 1.690 non-sudden deaths found that the involvement of a multidisciplinary palliative home care team was strongly associated with home death.[30] The rate of home deaths in the exposed and unexposed groups of our study, respectively 56.2% and 13.8%, was comparable with findings from an Italian study that compared the home death rates between users of palliative home care versus non-users (respectively 60.8% and 29.3%). Although we were not able to take into account individual preferences on place of death and quality of death itself,[31] our results show that the palliative home care support was effective in increasing the chance for home deaths on a population level, which is an important policy goal.[32]

Additionally, our study found that the use of palliative home care support has an impact on reducing hospital, ED and intensive care unit admissions in the last 2 weeks of life. This finding is in line with previous research,[17 20 33] but our study is the first to confirm such findings on a complete population level.

Strikingly, only 14% of all home-dwelling adults who died in Belgium in 2012 used palliative home care support in the last 2 years of life. This uptake is far below the actual need in the Belgian population for palliative care, which the most conservative estimation has set at 40% need in the population.[4] Currently, physicians in Belgium can grant patients an official 'palliative home care status' only when the estimated life expectancy is 3 months or less. Although this status does not exclude the patient from receiving specific types of healthcare, such as in the hospice benefit system in the USA, the life expectancy criterion possibly discourages physicians from offering palliative home care support, especially in younger and non-cancer patients, and removing it could increase the use and timely initiation of palliative home care support. Further research should also be done to investigate the implications of accessing support at a different period in the disease trajectory on the quality and costs of care at the end of life.

Strengths and limitations

An important strength of this study is that, by using nationwide administrative data on every death over one whole year, our findings are generalisable to the full population, whereas experimental studies, surveys or sample-based observational studies often have difficulties in reaching certain under-represented subgroups and lack the strength necessary for generalisability.[3] Second, we used a previously validated set of QIs specifically developed to evaluate end-of-life care on a population level.[25] This allows comparing appropriateness of end-of-life care between different populations, both nationally and internationally. This approach is particularly useful for those parts of the healthcare sector that do not deliver direct individual patient care, such as health service researchers, public health and other policy makers.[34] Our operationalisation of palliative home care support as the use of any of available supportive measures increases the reproducibility of our study in other countries and allows comparison studies that focus on the impact of other existing types of palliative home care support. Other countries that have palliative home care support measures can use the same methodology to measure the impact of their measures on the quality and costs of end-of-life care. Additionally, countries that have no or other palliative home care support measures can use our results to research the possibility to implement such measures in their own healthcare system. It should be noted however that the generalisability of the results remains largely limited to countries or regions with similar healthcare delivery and funding systems.

Another strength of using administrative data is that, compared with other data collections methods, it is relatively inexpensive to collect data for a large population without causing any burden to potentially vulnerable people.[35] In Belgium—where health insurance is

obligatory—administrative health claims data provide information on 99% of the population's healthcare use. Moreover, propensity score matching as a causal inference technique for treatment effect estimation in large observational studies is a particularly useful method when a traditional randomised controlled trial design is not feasible nor ethical, as is the case for our research questions.[16]

Our study also has limitations. Even though our matched cohort study allows to cancel out several sources of confounding, it does not account for unmeasured covariates, such as patients' or caregivers' personality features, knowledge of and preferences with regard to the end of life, which can influence both home palliative care support use and the outcomes we evaluated. It cannot be ruled out, therefore, that the strong association between palliative home care use and the characteristics of end-of-life care reflect underlying choices by patients, caregivers and family that impact both. For instance, to receive the palliative home care support in our study, patients should have a wish to die at home, which has been found to be an important predictor for actual home death.[28] However, even if it would be that patients needed a certain knowledge, attitude or mental switch to use palliative care, our results show that in these groups, quality of life increases and cost decreases. Although the circumstances of palliative care decisions clearly warrant further investigation, as they are still only partially understood, our findings are relevant information for policy makers to convince people of the added value of palliative care.

The use of retrospective data also has limitations. Because palliative home care support is in reality often used relatively late in the disease trajectory, we chose to restrict the outcome measurement period to the last 14 days of life to restrict the number of persons excluded from the intervention group. An additional limitation of using administrative data is that important aspects of quality end-of-life care that are not reimbursed, such as communication, existential or psychological care, are not visible. The QIs are not meant to serve as indicators for (in)appropriate care at the level of the individual patient, because clinical factors that justify an intervention and personal preferences can vary widely across patients. However, they are deemed valid at a population level. Our findings should be interpreted as an evaluation of the supportive policy measures for palliative home care on the aggregated level.

CONCLUSION

Palliative home care is an important part of end-of-life care. Those who want to be cared for at home and want to die at home have the right to use support to receive appropriate home care at the end of life. The findings from our nationwide retrospective matched cohort study show the positive impact of palliative home care support on the quality of end-of-life care. Additionally, we found that while the total costs for home care is higher, the average total reimbursed costs of medical care at the end of life is significantly lower for those who used palliative home care support. Our findings based on complete population national data add important scientific evidence of the positive impacts palliative home care support has on the appropriateness of end-of-life care and on reducing societal costs related to care at the end of life. Because palliative home care support appears widely underused, our results suggest that increasing its availability and stimulating its use, therefore, has a potential to improve the appropriateness of care at the end of life of patients and at the same time reduce the expenses for the health insurer.

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